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Ms. Joy Cramer
Deputy Minister of Families
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Dear Deputy Ministers Karen Herd and Joy Cramer:

Re: A discriminatory hierarchy of services for adults with severe disabilities

Introduction

I represent Amelia Hampton and Tyson Sylvester who independently contacted our office with respect to their efforts to obtain adequate community living supports for adults (like themselves) with significant physical disabilities.

Amelia and Tyson are young adults who require assistance with all aspects of their daily activities because of the nature of their physical disabilities. While Amelia and Tyson require assistance 24 hours/day, they currently receive an inadequate patchwork of rudimentary services.

Amelia and Tyson fall through the cracks of the policy and legislative regime of service provision for persons with disabilities in three main ways:

1. When individuals are over 18, they are no longer eligible for the Children disABILITY Services Program (CDSP).
2. Persons with physical disabilities do not qualify for Community Living disABILITY Services (CLDS), a parallel adult program of the CDSP, if they do not have a mental disability.
3. For adults without mental disabilities, the MHCP provides a maximum of approximately 50-55 hours of home care a week. The provision of the MHCP services is inadequate because:
 - the amount of hours is insufficient for Applicants who require 24/7 care for their health and safety and
 - the MHCP is based on a medical model of service delivery and creates insurmountable barriers for individuals who want to

remain in their communities.

These gaps represent a systemic failure. It is so widely recognized that health and social service providers have coined the expression "gappers" to refer to persons (like Amelia and Tyson) who fall through the cracks in policy and legislation. This situation creates a hierarchy of disability and perpetuates the stereotype that people with physical disabilities are less worthy than others. It sends the message that society will not benefit from the Amelia and Tyson's inclusion and that they are not worthy of equitable and adequate services.

Amelia and Tyson will be filing complaints to the Manitoba Human Rights Commission alleging that Manitoba Health, Seniors and Active Living (MH), Manitoba Families (MF) and the Winnipeg Regional Health Authority (WRHA) have failed to provide them (as well as other adults with significant physical disabilities) with adequate services contrary to ss. 9(1), 9(3) and 13(1) of the *Manitoba Human Rights Code* ("Code").¹ The Manitoba Human Rights Commission has already been made aware of Amelia and Tyson's situation and we would be prepared to engage in pre-complaint discussions with the respondent organization.

Specifically, Amelia and Tyson would like to discuss the Province's plan to address the gap of services and propose the creation of a community living program for adults with physical disabilities to have access to adequate and quality supports to live independently in their community.

Amelia and Tyson

Amelia and Tyson are 23 and 20 respectively. They value human interaction and enjoy spending time with family and friends. Both Amelia and Tyson have had cerebral palsy since birth. Specifically, Amelia has cerebral palsy with spastic quadriplegia and she is non-verbal. In addition to having cerebral palsy, Tyson also lives with a severe visual impairment.

Amelia and Tyson require assistance in all aspects of their day-to-day life, including feeding, dressing, toileting and going to bed. This assistance is needed to ensure their well-being and safety.

Amelia's primary caregivers are her parents. While she requires 24 hour care per day, Amelia is only eligible for 55 hours of home care per week. She is part of the minority of home-care clients whose mother is paid for 45 hours per week under the Family Managed Care Program of the Manitoba Home Care Program (MHCP). The remaining 55 hours is provided to her through respite services.

Tyson lives at _____ and relies on his mother for support. Tyson also requires 24 hours of care per day but he is only eligible for a maximum of 50 hours of home-care per week. This assistance is provided by MHCP and typically consist of four 15-25 minute visits per day. Tyson relies on his home-care visits to assist with him with his rudimentary needs (getting out of bed, toileting, eating, taking medication, dressing, getting back into bed).

¹ *The Human Rights Code*, CCSM 2015, c H-175 s 9(1)(2)(3), 13(1) [Code].

Patchwork of Services Provided by Manitoba Health and Manitoba Families

It is our understanding that MH and MF are provincially responsible for administering support and community service programs for persons with disabilities. The following briefly describes the four programs that define the patchwork of services offered to persons living with disabilities in Manitoba:

1. the Children's disABILITY Services Program (CDSP);
2. Community Living disABILITY Services (CLDS) Programs;
3. the Manitoba Home Care (MHCP); and
4. the Personal Care Home Program (PCHP).

CDSP - The CDSP provides services essential to meeting the physical and social needs of children with disabilities and it is delivered through the school system. Children are eligible for CDSP if they are seventeen (17) years or younger, if they are living with their birth or extended or adoptive families in Manitoba, if they have a mental disabilities, a developmental delay, an autism spectrum disorder or a lifelong, physical disability that results in significant limitations in mobility.

CLDS - The CLDS offers a range of day and residential services for adults with intellectual disabilities. The program aims to provide individuals with intellectual disability the opportunity to lead satisfying, productive lives in their communities, to make their own decisions and direct their own lives as independently as possible. There is no equivalent program for adults with physical disabilities.

MHCP - Adults with physical disabilities typically rely on MHCP for services. However, MHCP is a program that is strictly limited to personal and medical care. It's mandate is twofold:

1. to ensure provision of effective, reliable and responsible home healthcare services for Manitobans to support independent living in the community; and
2. to ensure co-ordination of admission to facility care when living in the community is not a viable alternative.

The WRHA administers the MHCP. The WRHA's authority flows from the *The Regional Health Authorities Act*². The Act ensures that "health services are provided in a manner that is responsive to the needs of individuals and communities in the health region"³.

PCHP – Personal care homes are meant as last resort. They provide personal care services to individuals who can no longer manage independently at home with supports and generally speaking, they serve an older age demographic.

² The Act states that "health services are provided in a manner that is responsive to the needs of individuals and communities in the health region. See: *The Regional Health Authorities Act*, CCSM (2014), c R-34.

³ *Ibid* at s 23(2)(h).

Amelia and Tyson Received Appropriate Services Until They Graduated from High School

Until they graduated from high school, Tyson and Amelia were eligible for a vast array of personal and educational services offered by the CDSP, funded through their public school boards and through Manitoba Families.⁴ Specifically, the Special Needs Categorical support provides an in-depth accommodation for students, including adaptive resources and technologies. Amelia and Tyson had one-on-one supports all day at their schools. They also had access to respite, occupational therapy, physiotherapy, rehabilitation, after-school care, supplies and equipment, social activities outside the home and transportation to and from appointments and school.

The CDSP enabled Tyson and Amelia to live as independently as possible in their own community in a way that respected their self-worth and valued their dignity.

Reaching Adulthood and Losing Access to Critical Supports

During their transition from youth to adulthood, Amelia and Tyson went from receiving a full suite of supports to suddenly being left with only the most rudimentary assistance which does not meet their social needs. This transition has created an enormous strain on Amelia and Tyson and their families.

Pursuant to the eligibility criteria of the Children's disABILITY Services, when Amelia and Tyson turned 18, they were no longer eligible for the majority of services provided by Children disABILITY Services Program. For example, Tyson had access to a screen reader which enabled him to use the internet, empowering him to learn, communicate, socialize and perform important tasks such as banking and shopping. His screen reader was removed right after his graduation, leaving him in isolation. In Amelia's case, when she was under 18 years old, the cost of the van conversion was covered by Children Special Services ("CSS") so that it could be equipped with a lift and tie-downs for her wheelchair. CSS also covered the ongoing maintenance costs of the van until Amelia turned 18. As soon as she turned 18, this type of financial assistance was no longer available to Amelia and her family.

A major challenge for both families is the lack of assistance with transitioning from youth to adulthood. As indicated in a recent CBC Manitoba News article,

Provincially funded services are great but are taken away when needed most.[...] Legally when you turn 18 you're an adult. Hopefully, one day the government will realize that disabilities see no age.⁵

The lack of information and assistance in navigating the patchwork of supports adds stress to an already difficult situation.

⁴ Amelia attended Maples Collegiate High School and Tyson attended Transcona Collegiate.

⁵ Alex Lytwyn "Survival of the weakest: Manitobans with disabilities left without services" (June 15 2016) available online: <http://www.cbc.ca/news/canada/manitoba/manitoba-disabilities-services-alex-lytwyn-commentary-1.3633598>

IQ Testing: A demeaning quest for appropriate services and a flawed interpretation of existing policies

In order to qualify for the CLDS, a person must be considered to be “vulnerable” under *The Vulnerable Persons Living with a Mental Disability Act (VPA)*.⁶ The Department's policy states that it relies on the Diagnostic and Statistical Manual of Mental Disorders (DSM) to determine eligibility. While the outdated DSM IV defined “mental retardation” as an “intellectual functioning (an IQ of approximately 70 or below)”, the current DSM V includes a more holistic definition and does not refer to the IQ test. It states that an “intellectual disability”:

is characterized by deficits in general mental abilities, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience. The deficits results in impairments of adaptive functioning, such that the individual fails to meet standards of personal independence and social responsibility in one or more aspects of daily life, including communication, social participation, academic or occupational functioning, and personal independence at home or in community settings.

As you may know, the Fifth Edition of the DSM was released in 2013. However, based on our experience, the Department continues to rely on the IQ test to determine eligibility of the CLDS Program.

In a desperate attempt to receive services, Tyson has taken the IQ test. Despite the fact that Tyson requires individualized services which are provided by CLDS, his IQ test score was 70 and therefore he was deemed ineligible for these services. Tyson's experience taking the IQ test was very negative.

Amelia has not taken the IQ test given her and her family's view that the test is demeaning and flawed. In Amelia's case, it would be challenging at best to take the test based on her physical disabilities.

Given the ad hoc and rigid nature of the test, many have argued that determining eligibility for the CLDS based on the IQ test is not a true reflection of individual needs. It can be argued that relying on the IQ test is discriminatory and contrary to the VPA's legislative intent to provide support services for adults with intellectual disabilities based on their needs.

Tyson and Amelia view not being eligible for CLDS as a punishment for having the “wrong kind of disability”.

6 *Vulnerable Persons Living with a Mental Disability Act, CCSM (2014), c V-90.*: Section 9 of the VPA, allows the Minister to “provide or arrange for the provision of support services for a vulnerable person.” A “vulnerable person” is defined under s. 1(1) of the VPA as an adult living with a mental disability in need of assistance to meet their basic needs. A “mental disability” is defined as “significantly impaired intellectual functioning existing concurrently with impaired adaptive behaviour manifested prior to the age of 18 years.” The Program's Eligibility Policy provides that in order to determine whether individuals have “significantly impaired intellectual functioning”, there must be a “current and conclusive” intellectual assessment.

Inadequate home-care services lead to isolation and despair

Amelia lives with her parents. Despite requiring 24 hours per day of home-care, she receives a total of 55 hours of home-care per week. She is part of the minority of home-care clients whose mother is paid for 45 hours per week under the Family Managed Care Program.⁷ The remaining 10 hours is provided to the Applicant and her parents through respite services.

Tyson lives on his own at [redacted]. He requires 24 hours of home-care per day, however he receives a maximum of 50 hours per week. Tyson's home-care services are funded by the MHCP and provided by the Access Transcona Office of the WRHA. Tyson relies on this program and on his family in order to live independently and remain in his community. On a daily basis, a home-care worker is dispatched for 15 to 25 minutes to help him bathe, dress and go to the washroom. When home-care is not available, Tyson is home alone.

The services provided by the WRHA are limited to medical and personal care. Home care workers provide assistance with bathing, feeding, medication and personal hygiene. Home-care workers are not able to accompany clients outside their home. Specifically, they do not offer companionship, shopping or transportation services.

There are no educational requirements for home-care workers. Many of them have not received any training to transfer patients from their bed to a wheelchair. This is particularly troublesome for Tyson as he is unable to leave his chair for personal care purposes.

Home-care does not provide any consistency of care. Tyson often receives visits from different and unfamiliar workers. Workers are usually rushed and unaware of his needs. This is troubling and frustrating because he is obliged to re-explain his medical or current needs, leaving workers little time to actually assist him. For example, a worker explained something to Tyson by gesturing, without realizing that he was visually impaired. Tyson has also been dropped during a transfer by a new home-care worker, which caused him trauma and resulting in a sprained ankle.

Since Manitoba home-care services does not have the authority to transport clients off-site, the Tyson is left indoors all day and has nothing to do but use his computer. If he needs to use the toilet – a basic human need – he must wait hours until the next home-care visit.

The lack of consistency in home-care workers creates a situation where Tyson cannot develop meaningful relationships with anyone but his mother. His lack of human interaction causes him extreme loneliness, which impacts his self-esteem and confidence, and limits any chance of self-actualization.

If Tyson and Amelia's families become unable to care and support them, the service structure is such that they would need to move to a personal care home. However, personal care homes

⁷ The Family Managed Care Program is a Home Care Program under which funding equivalent to the cost of home-care is provided to family members of Home Care clients taking responsibility for arranging, coordinating and managing non-professional services required to meet their family members home care needs.

are not designed to meet the needs of young adults. The recent Auditor General Report which examines the Home Care in detail does not include any recommendations specific to addressing the needs of persons with disabilities.⁸ The Report finds that most home care clients were 65 or older.⁹ It indicates that the strategic direction for the Manitoba Home Care Program is its plan for “successful aging” and “continuing care”.¹⁰

Living in a personal care homes would not enable Amelia and Tyson to lead satisfying and productive lives in their communities. Life in a personal care home would be further isolating for them; they would lack stimulation appropriate to their age and abilities, and it would be difficult for them to find meaningful companionship.

The families have suffered significant emotional strain as a direct result of the lack of supports. Sadly, this situation is so widely recognized that health and social service providers have coined the expression “gappers” to refer to persons (like Tyson and Amelia) who have lost supports and services and fall through the policy and legislative cracks. Letters of support from the Cerebral Palsy Association of Manitoba, Independent Living Resource Centre and the Manitoba League of Persons with Disabilities have flagged the seriousness of the issue for many other Manitoban families.¹¹

Potential Legal Vulnerabilities

Tyson and Amelia have the right to live free from discrimination on the basis of disability and age when receiving services. As previously stated, Amelia and Tyson will be filing complaints to the Manitoba Human Rights Commission alleging that Manitoba Health, Seniors and Active Living (MH), Manitoba Families (MF) and the Winnipeg Regional Health Authority (WRHA) have discriminated against them (as well as other adults with significant physical disabilities) in the provision of services contrary to ss. 9(1), 9(3) and 13(1) the *Manitoba Human Rights Code* (“Code”).¹²

Their complaints will allege a prima facie case of discrimination on the basis of disability and age by describing the existing gap of services for adults with physical disabilities. Individuals with lifelong physical disabilities who are under 18 years old qualify for CDSP, but individuals with the same physical disability who are 18 years-old and older do not qualify for CLDS, the parallel adult program. This distinction in provision of services by the Government seems be rooted in a false and ableist presumption that it is somehow easier for an individual over 18

8 Auditor General of Manitoba, “Department of Health, Healthy Living and Seniors Winnipeg Regional Health Authority Southern Health-Sante Sud” (2015) <http://www.oag.mb.ca/wp-content/uploads/2015/08/Manitoba-Home-Care-Program-Report-Web-Version2.pdf>

9 *Ibid* at p 11.

10 *Ibid*.

11 Please see the attached Letter of Support from the Cerebral Palsy Organization of Manitoba

12 *Code*, *supra* note 1: According to s. 13(1) of the *Human Rights Code* (“Code”), no person shall discriminate with respect to any service or accommodation unless bona fide and reasonable cause exists for the discrimination. Discrimination is defined in the Code at subsection s. 9(1) as differential treatment of an individual on the basis of their protected characteristic(s) as well as the failure to make reasonable accommodations for special needs. According to s. 9(3), systemic discrimination based on protected characteristics is also contrary to the Code. Subsection 9(2) of the Code outlines the protected characteristics which include age and physical disability.

with physical disabilities to live without full care, than it would be for a 17 year-old.

However, disabilities see no age. This presumption does not take into consideration the actual circumstances and needs of individuals turning 18 who have physical disabilities. There is no way to justify such a pronounced discrepancy between the two groups.

The Government appears to have made the assumption that there exists a moral obligation for families to care for their relatives. This assumption results adverse and stereotypical treatment that ignores one's autonomy and dignity as an individual. In fact, the resolution of human rights complaints in Manitoba has resulted in a recognition that we cannot deny or reduce benefits to adults with disabilities based on the assumption that family will close the gap of provision of services.

The Provinces (in)actions with respect to services for adults with physical disabilities such as Amelia and Tyson is also contrary to the spirit and intent of *The Accessibility for Manitobans Act (AMA)* as well as the *Convention on the Rights of Persons with Disabilities (CRPD)*.

The AMA was enacted as law in 2013. By virtue of the AMA, the Manitoba Government expresses a commitment to remove barriers for all persons with disabilities that deny the rights and responsibilities to full citizenship. According to s. 3(2), a "barrier" can be "established or perpetuated by an enactment, a policy or a practice". According to the AMA, the Minister responsible for Persons with Disabilities has the mandate to promote and encourage the prevention and removal of these barriers.

The CRPD was ratified by Canada in 2010. This Convention recognizes the right of persons with disabilities to full and effective participation and inclusion in society.¹³ It indicates that states shall "take effective and appropriate measures to facilitate the full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community."

Through its ratification of the CRPD, Canada is bound under international law to comply with the rights set out in the Convention. The Canadian government has stated that the obligations of the Convention could be complied through the reliance of the *Canadian Charter of Rights and Freedoms*, the *Human Rights Act*, and equivalent provincial and territorial legislation.¹⁴

At a minimum, the Provincial Government must use the CRPD as an interpretive tool for its actions relating to persons with disabilities.

The rights established in the *Canadian Charter of Rights and Freedoms* should also be used as interpretive tools and guiding principles by the Provincial Government. Section 15(1) of the Charter provides that

"[e]very individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex,

¹³ See article 3 and 19.

¹⁴ *Ibid* at 4.

age or mental or physical disability.”¹⁵

First and foremost, this section expresses a commitment to equal worth and human dignity of *all* persons. Interpreting this right, the Supreme Court of Canada has recognized that it is unfair to limit an individual's full participation in society solely because the individual has a protected characteristic described in section 15(1).¹⁶

As young persons with disabilities, Amelia and Tyson are experiencing discrimination based on the intersecting grounds of discrimination of disability and age. Because of these protected characteristics, neither Amelia and Tyson have access to services which enable their social inclusion. The SCC has acknowledged the long standing disadvantage experienced by persons with disabilities.¹⁷ The Province's failure to provide adequate and equitable services to Amelia, Tyson and other individuals in similar circumstances perpetuates the prejudice of a historically disadvantaged group. It also promotes the stereotype that persons with disabilities are “less valuable” than able-bodied persons.

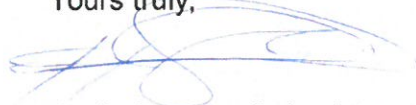
Conclusion

In conclusion, we would ask whether the Province is prepared to engage in pre-complaint discussions. The purpose would be to discuss the Province's plan to address the gap of services and propose the creation of a community living program for adults with physical disabilities to have access to adequate and quality supports to live independently in their community.

It is our understanding that a review of the Manitoba Home Care Program may already be underway. Should this be the case, we would ask the Ministers Responsible to recognize that this Program is based on a medical model and focuses on disability as something that needs to be 'treated' or 'cured'. Instead, Amelia and Tyson would ask the Province to concentrate on how to address the social barriers that preclude persons with disabilities from participating in their communities and in the workplace which will require the creation of a new program.

We look forward to your prompt response to this letter.

Yours truly,



Joëlle Pastora Sala, Attorney
/JPS

15 *Canadian Charter of Rights and Freedoms*, s 15, Part I of the *Constitution Act, 1982*, being Schedule B to the *Canada Act 1982 (UK), 1982*, c 11 [Charter].

16 *Quebec (Attorney General) v A*, 2013 SCC 5 at paras 137-138 [*Quebec v A*].

17 *Eldridge v British Columbia (Attorney General)* (1997), 3 SCR 624, 151 DLR (4th) 577.